



SPINAL COURIER

SPINAL CORD
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Horace Love to Lead Peer Support Network

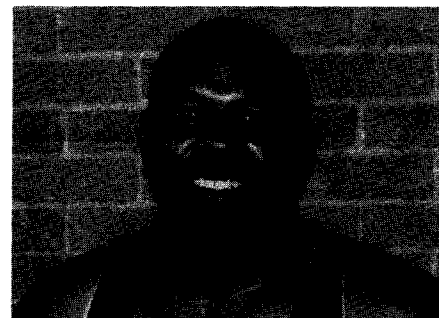
"You don't know how I feel or what I'm going through." That's the cry of many newly injured spinal cord individuals who are trying to deal with the sudden changes in their life. In order to provide assistance to these individuals, the Commission is establishing a new Peer Support Network. Upon request, the Peer Support Network will assign a trained Peer Consultant to work with the SCI client and family.

The Peer Support Network is not a counseling service. Instead it offers an opportunity for newly injured clients to talk with someone

who has been through a similar experience. Peer consultants provide support, guidance, share information, and are good listeners.

Horace Love has accepted the position of Peer Support Coordinator and will be organizing this effort. He is a native of North Carolina and has a BS degree in Marketing from UNC-Wilmington. Horace is a paraplegic who was injured in June, 1991.

Peer Counsultant training will begin in October with the Network beginning operation at the end of November, 1993.



Peer Consultants must be well adjusted persons with good communication and coping skills who have been discharged from Rehab for at least six months. If you or someone you know have the qualities of a Peer Consultant, call Horace Love at 324-9620.

Commission Survey Sheds New Light on Arkansans with Spina Bifida

The Arkansas Spinal Cord Commission, in cooperation with the Spina Bifida Association of Arkansas, conducted a statewide survey this year of all Arkansans with spina bifida. The purpose of the study was to describe this group and to determine the number and type of secondary disabilities that individuals with spina bifida have. The information will be used to assist the Commission in providing appropriate services for clients with spina bifida.

The Commission's casemanagers administered the survey to the clients on their caseload. Out of 428 identified persons with spina bifida across the state, a survey was returned for 380 individuals. Because of the large number and wide variety of conditions addressed on the survey, it will take

some time to perform a comprehensive analysis of all items. However, a general description of the individuals with spina bifida residing in Arkansas has been conducted and highlights follow below:

Gender: Out of the 380 individuals surveyed, 53% were males and 47% were females.

Race: 84% of the clients were white, 14% were black and 2% were of another race.

Age: Although ages range from under 1 to 62, spina bifida individuals in Arkansas are generally young with an average age of 16.

Marital status: Because of their young average age, only 5% have ever been married.

Living arrangements: The vast majority, 83%, live with their parents, 6% live with their spouse or roommate, 5% live in a group unit, 4% live alone and 2% have other living arrangements.

Employment: 54% are not old enough to work, 34% do not or are not able to work, 6% are employed in competitive positions, and 5% are employed in non-competitive positions.

Income assistance: 61% receive SSI, 4% receive SSDI, 4% receive some other type of income assistance, for 2% no income information was available and 29% received no income assistance.

Mobility: 45% fit the definition
See Survey, page 8

SPINAL COURIER

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BUCKLE UP!

SPAY/NEUTER ARKANSAS IS NOW OPERATIONAL

The Spay/Neuter Arkansas program is off to a great start. It will provide low-cost neutering, heart worm check and rabies shots for animals belonging to low-income elderly and low-income disabled. It is a joint effort developed by Frances Thomas of Arkansas Animal Birth Control Association and AFA, with affiliated Humane Societies - Lonoke, S.E. Arkansas, South Mississippi County, and Animal Service agencies such as Hot Springs and Fayetteville.

Arkansas is the first state to have such a program that is 1.) state-wide, 2.) not publicly funded in any way, and 3.) does not have its own clinic. Of course, this program would not be possible without the support and dedication of the participating veterinarians from nearly every area of the state who have committed their talents, training and practices to the welfare of animals and their communities.

For more information call the program director, Rita Cavanaugh, at 661-1069.

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Flu Vaccine

This is a reminder that the flu season will soon be here and a severe epidemic is predicted for this year. It is strongly recommended that quadriplegics receive the flu vaccine as well as anyone else subject to frequent respiratory infections.

JOHN ENRIGHT WHEELING USA!

John Enright with be pushing 15,000 miles across the United States in late October to help raise monies for "Will the Power." This nonprofit group sets up educational scholarships for persons with disabilities.

Fort Smith Rehabilitation Hospital (FSRH) is sponsoring John's efforts and will match funds that will be raised from FSRH employees and interested persons and organizations wanting to support this educational scholarship fund. If you are interested in making a donation, please contact Cindy Shaw at Fort Smith Rehabilitation Hospital at 785-3300.

Clydale Dutton Passes GED

Clydale Dutton, age 62, recently passed his high school General Education Diploma. A resident at Geriatrics Nursing Center, Dutton studied for the exam over a six month period with a group of certified nursing aides who worked at the Center.

Born with spina bifida Dutton never received any public schooling; he was taught to read and write by his mother. Mr Dutton said that he would like to own his own business some day but, in the meantime, he has enrolled at the Mid-South Community College where he will be taking English composition and elementary algebra. Congratulations Clydale!



Equine-Assisted Therapy

Dear Editor:

In response to prompting by my ASCC case manager Bettie Tapp and your January, 1993 article about Ravenswood Equestrian Center, I began passive riding twice a week in April of this year. The horse's rhythm is much like that of human gait and the rider's brain is tricked into believing that the body is walking again. Torso muscles are strengthened and others follow suit. This therapy program is not a cure, but it is lessening some of the symptoms of my hereditary Ataxia disorder.

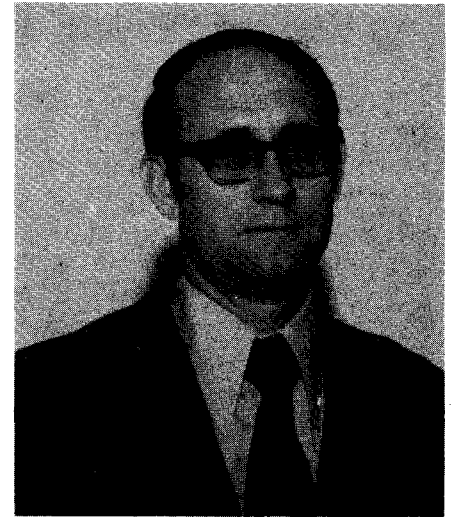
I seem to be improving: 75% of my nystagmus has disappeared - something many doctors didn't think was possible. Swallowing and breathing are easier (I don't choke on foods anymore!), my speech and penmanship are becoming noticeably clearer, my posture has greatly improved, my energy levels are higher and my overall attitude is improving with every session.

Besides being good for your body, this therapy program gets you out in Arkansas' natural beauty and it's FUN! C'mon, join us!

Judy Cox, Hot Springs

HIGH PROFILE!

CHARLES CROWSON



This is the first in a series of articles profiling the ASCC Case Managers

Over the past 27 years there have been many individuals' lives changed for the better because Charles Crowson made his decision to pursue a career in Rehabilitation Services. His work as a case manager is an integral part of his life and as Charles puts it, "This job was made for me. In 1966 a close friend of mine, who was a Rehabilitation Counselor, convinced me it was a worthwhile job and I've never regretted my decision."

Charles' early background in construction, serving as an Army Engineer, and earning a Bachelor's degree in Industrial Education, reinforced his desire to create adaptive equipment to assist individuals with disabilities. "I've always liked building and making things for people, especially something that will make life a little easier and help increase independence." Throughout the years Charles has become affectionately known by his co-workers as the "Wizard of Invention" because of his ability to repair, design and build equipment. He is very modest about his creativity and ingenuity, "I just enjoy trying to help people meet their needs."

Often Charles' unique ability is the sole resource for a person living in a remote rural area in Northern Arkansas. Some of the different equipment Charles has designed to meet specific client needs include: a home elevator to

enable an individual to go from his basement to the first floor, a battery-powered Jeep allowing a little girl to go outside and play with other children (the yard was so hilly and rough she couldn't use her wheelchair independently), and a lift for a pickup which lifted a wheelchair in and out of a truck-bed. If he could not be a case manager, Charles would be an inventor, "so I could invent more things to help people with disabilities."

Charles' office is in Batesville, but he spends most of his time on the

rural roads of Northern Arkansas covering ten counties, visiting clients anywhere from Peel to Tupelo. The hours 8:00 a.m. to 4:30 p.m. do not fit into Charles' vocabulary, nor his schedule. There are days when he is on the county highways before daylight and often does not return before the sun sets. To put it into Charles' words, "You don't come home 'till the job's finished."

FAVORITE HOBBIES: "Fishing and hunting."

MOST VALUED POSSESSION: "My family."

FAMILY MEMBERS: "Wife, Norma, two daughters, two grandsons ages 6 and 15, one granddaughter age 10, and one grandchild on the way!"

FAVORITE PLACE TO UNWIND: "Actually two different places; any good fishing spot and the fitness center."

FAVORITE THINGS TO DO WITH THE GRANDCHILDREN: "Take the boys fishing and take my granddaughter out to breakfast on Saturday morning, so just the two of us can talk and spend time together."

ADVICE TO A NEW CASE MANAGER: "If you don't love people and don't have empathy, find another job."

PHRASE TO SUM ME UP: "I hope people would say, 'he's dedicated, sincere and empathetic'."

MY BEST WORDS OF WISDOM: "It's an old slogan with a twist -- you only go around in life once, so make it count."

BEST ADVICE FOR A PERSON WITH A DISABILITY: "Never give up!"

YES, You Can!

A Guide To Self Care for Persons With Spinal Cord Injury

YES, You Can! For many newly injured individuals, these three short words sometimes seem to be nonexistent. Figuring out how to do simple things (like emptying your bladder) again, as well as more complex things (like returning to work), seem to run into a wall of no's, not's and can't's.

YES, You Can! is about independence. It is about doing things again, taking charge of you life and making things happen.

YES, You Can! is an "everything you ever wanted to know about living with a spinal cord injury"... and then some. Marshall Purvis of Little Rock, a former ASCC Commission Member who has lived with quadriplegia for over 35 years calls it "the most complete resource I've ever seen. Every person with a spinal cord injury should have one!"

YES, You Can! is an owner's manual for spinal cord injury (SCI). A loose leaf 155 page manual, it is written for people with SCIs and their families. Chapters cover topics from anatomy and physiology to respiratory care and nutrition to driver's training and attendant management. The technical assistance (like how to build a ramp or how to hire an attendant) is excellent.

Editor Margaret Hammond, MD and her staff at the Seattle VAMC have designed a great resource. Paralyzed Veterans of America are publishing it at a price that everyone can afford (\$9.50 plus \$2.50 shipping). To get a copy send \$12.00 to PVA c/o Office Services, 801 Eighteenth St., Washington, D.C. 20006.

Should you get a copy? Yes, You Should!

When Your Child is Seriously Injured: The Emotional Impact on Families

It's always much easier to do something if you've done it before. Experience is always the best teacher. With most things, if you need experience doing something, you can either practice it or just go out and do it. Some things are so painful to learn, however, that once is more than enough. Sometimes once is too much. Having a child become seriously injured is just such an instance.

Marilyn Lash, the Director of Training at Tufts University's Department of Rehabilitation Medicine recognizes the value of experience as a teacher. In her 1991 book *When Your Child is Seriously Injured: The Emotional Impact on Families*, Ms. Lash puts the experiences of other parents to good use. This guide to parents and siblings of an injured child is full of practical advice on every aspect of acute care, hospitalization, and transition back to the home. Ms. Lash does not write from a posi-

tion of expertise. The expertise in this book comes from the families of injured children she has interviewed. It discusses the families' methods of coping with feelings of anxiety, responsibility and guilt, and the effects those feelings can have upon other family members. It discusses families' efforts at adjusting to the changes they and their injured family member will have to make. Finally, it lists coping strategies that have been used successfully by these families in a wide variety of situations.

This is a very sensitive, helpful and well written book. The artwork, by the children of the interviewed families, is wonderful as well. *When Your Child is Seriously Injured: The Emotional Impact on Families* is available in the ASCC Resource Library. If this sounds like something you would be interested in reading, please contact Loretta Decker at 324-9628 for your very own copy.

1993-94 Wheelchair Basketball Schedule

Rollin' Razorbacks

Dates	Location
Nov. 13-14	Home
Dec. 17-19	Dallas, TX
Jan. 8-9	Home
Jan. 15-16	Nashville, TN
Feb. 18-19	Birmingham, AL
Feb. 26-27	Home

All home games played at Sylvan Hills High School, Highway 107 in Sherwood, Arkansas.

Shootin' Stars

Dates	Location
Nov. 6	AR Valley Tourney
Nov 14-15	Little Rock, AR
Nov. 20	Muskogee, OK
Dec. 4	Oklahoma City, OK
Dec. 11-12	Memphis, TN
Dec. 18	Tulsa, OK
Jan. 8	Oklahoma City, OK at home
Jan. 22	Tulsa at home
Jan 29	Muskogee, OK

Home games played at Westark Community College in Fort Smith, Arkansas.

Post Season Schedule

Mar. 12-13	Regional Tournament
Mar. 26-27	Sectional Tournament
Apr. 7-9	Final Four Championship, San Jose, CA

AUTOPSY OF A WHEELCHAIR

It was supposed to last me five years or more,
It's hardly lasted for two.
How could it happen that one little woman
Could annihilate her chair of blue?

I'm not an athlete, not even physically fit,
And my life is certainly quiet.
So why does it look as if my chair
Survived the effects of a riot?

The wheels buckle in, the sides buckle out,
And there's talcum powder everywhere.
Maybe next time I can possibly get
A self-cleaning wheelchair.

The enamel's chipped, the vinyl's shredded,
And the front wheels are snarled with hair.
The wheelie-bars drag and the seat sags
On my poor little wheelchair.

There's rust in the places where I tried to scrub
To keep my wheelchair neat.
So, like the Tin Woodsman, I can hardly move
Without making joints whistle and squeak.

It's obvious to me that the chair has shrunk
From all the scrubblings it's received.
It can't be that I've expanded and pounds added on -
A concept too wild to be believed.

There are places on it that rub places on me
In areas I no longer feel.
The last thing I need, now that I'm in a chair
Are welts that take forever to heal.

Plans are in gear to create a new chair
That will be more convenient for me.
One that fits my proportions and living space
And continues to set me free.

Yes, it's served me well, this little chair
In that I cannot deny.
It's taken me all the way from here to there --
On that I've been able to rely.

My intention was not to spend the rest of my life
Posed in a sitting position.
But, thanks to 4-wheels, I can make it along
And carry on my independent tradition.

-- Written by P.I. Maltbie

FROM THE DIRECTOR

Health Care Reform! The President's Health Care Plan! Socialized Medicine! Access To Care!

Everywhere you go and everyone you talk to has an opinion on the state of health care in America. The opinions seem to alternate between awe and anger. Medical Technology has provided us with treatment that 40 years ago was unheard of. But many of us are angry that we can't get the basic health care we need. Where is it all going? Is there a magical plan that will meet all our needs? I for one am confused.

I've worked in health care all my professional life, I see myself as an advocate for the needs of people with spinal cord and other disabilities and I want to believe that there is an equitable way that people who need it can get good care. We know that good initial rehabilitation and appropriate equipment for people with spinal cord injuries is effective, in functional outcomes, in quality of life and in overall cost. We have example after example to show it's true. But 'the system' seems short sighted, looking at today, not tomorrow.

The federal systems like Medicaid and Medicare and also the insurance industry seem to have blinders on. Some states like Oregon have come up with systems that 'prioritize' and 'ration' health care to contain costs. But who is to say that someone with one disease or disability is less 'worthy' of care than another? The ADA says you can't discriminate by disability - not even in health care!

The answer? You've got me! But I know one thing for sure, I want to have some say in what happens. I've lived in this country for more years than I'd like to admit these days and plan to be around for quite a few more. I don't want to live in fear of growing old. A recent poll said 67% of Americans are afraid that their health care needs won't be met in the future, count me in that group.

What am I doing about it? Learning as much as I can about how the proposed plan will affect me and the people I work with and then letting the 'decision makers' (our President and Congressional representatives) know how I feel and WHAT I WANT AND NEED! If I don't, I may have to live with what someone else wanted - for the rest of my life!

Think about what YOU want and need in a health care system and make YOUR voice heard! The time is NOW!

Cheryl Vines

MEDICAL CONFERENCE REPORT

by Shirely McCluer, M.D.

From September 7-9, 1993, I attended the annual meeting of the American Paraplegia Society in Las Vegas. This is one of two national physician organizations devoted entirely to spinal cord injury. I will briefly discuss some of the topics that were presented.



Hunter Tree Stand Safety Addressed

The Arkansas Spinal Cord Commission (ASCC) and Arkansas Game and Fish Commission (AGAF) have produced and distributed a television and radio public service announcement about tree stand safety directed at the state's hunters. According to Marc Kilburn, AGAF Assistant Chief of Information and Education, "One-third of all deer hunting injuries in Arkansas each year are related to tree stands." Falls from tree stands can result in permanent spinal cord injury.

Pictured above, ASCC client Verlan McKay prepares to advise Arkansas hunters, "Check your tree stand before you use it. Don't let a wheelchair be your next piece of hunting equipment," as ASCC Health Educator Ann Whitehead reviews script and AGAF videographer David Settlemoir adjusts the camera. The public service announcements will run statewide during the 1993-4 hunting season.

Dr. Samuel Stover of University of Alabama in Birmingham gave an excellent special lecture reviewing what we have learned in the past 20-30 years about SCI and what we still don't know. For anyone interested in hearing it, we will be ordering an audio tape of the lecture for our library and the talk will be published in a medical journal soon. He stressed that respiratory complications are now the leading cause of death in SCI rather than urinary problems and we need to direct more research efforts into better respiratory management.

Gallstones: The risk for developing gallstones within 6 months after SCI (esp. levels above T10) is about 200 times higher than in the general population. The stones are usually composed of cholesterol and therefore may not show up on X-Ray, but can be detected by Ultrasound of the abdomen. The presence of the stones is not serious by itself, but they greatly increase the risk of acute gallbladder infections (cholecystitis) with possible rupture of the gallbladder, which can be very serious. This is of particular concern in SCI because the symptoms of the acute infection may not be recognized due to loss of sensation in the abdominal area. This should be discussed with your doctor when you have a routine exam, or esp. if you are having vague abdominal complaints which may be due to gallbladder disease. If gallstones are found, the possibility of surgical removal before you have symptoms should also be discussed.

Research: Several papers were given about animal research into what happens immediately after an injury to the spinal cord and trials with various chemicals or techniques to minimize the permanent damage. Although much has been learned, there are still many unanswered questions. No dramatic



new discoveries were presented.

Fertility: Several centers reported on their work with fertility in SCI males. These special clinics continue to improve in their ability to collect sperm using one or more of the available techniques (such as vibration or electro-ejaculation), but the success rate for pregnancy and live birth is still only about 30% in the best centers using all available methods and the process can be very expensive. Sperm collection is not recommended before one year post injury, and for some unknown reason, it does not seem to work as well in injuries due to gunshot wounds. (Unfortunately, we still do not have any such clinics in Arkansas).

Substance Abuse and SCI: There was much discussion of this problem and solutions that have been tried. It was generally agreed that persons with SCI do not benefit as much from traditional treatment programs, but so far there are very few alternatives available.

Bladder Cancer and SCI: The risk of bladder cancer is 10 times greater in SCI than the general population. Factors which seem to increase the risk are: smoking, frequent urinary tract infections, frequent bladder stones, length of time since injury, and possibly prolonged catheter use. Anyone who is 10 or more years since injury should have regular cystoscopy (looking into the bladder by a Urologist), at least every 2 years.

Copies of the program and abstracts of the papers presented are in the Spinal Cord Commission Resource and Education Center.

FIRST ANNUAL REACH FOR A STAR AWARDS BANQUET



Front row, left to right: James Taylor with parents standing behind, Larry Sipes, Grover Evans, Dana Matthews, Deanna Cathcart, Tom Withers and Jeanette Hogan. Second row includes parents, teachers, rehabilitation counselors, clients of other agencies and area business representatives.

Simpson Goes To Washington

President Bill Clinton has nominated Bobby Simpson of Little Rock to be the Commissioner of the federal Rehabilitation Services Administration. Mr. Simpson is presently the Commissioner of Arkansas Rehabilitation Services, a position in which he has served since January, 1989.

The Rehabilitation Services Administration (RSA) is a part of the Department of Education. It administers rehabilitation services including vocational rehabilitation, independent living and innovative specialized programs. Many of the funds utilized for services by State Departments of Rehabilitation, including Arkansas, come from RSA.

Bobby Simpson was born and raised in Texas, where he sustained his spinal cord injury at age 18 secondary to a motor vehicle crash which resulted in C5 quadriplegia. He went on to obtain both his Bachelors and Masters degree and has spent his professional career working in the field of rehabilitation. He came to Arkansas in 1985 as a Training Coordinator for

the Regional Rehab Continuing Education program at Hot Springs Rehabilitation Center.

Simpson worked closely with President Clinton while he was governor on issues such as supported housing, personal assistance and disability rights. During the presidential campaign, Simpson served as a key policy advisor on disability issues. Though he has been nominated, Simpson awaits Senate confirmation before he packs his bags for Washington.

"I really hate to leave Arkansas and my friends as well as the strong programs that we've developed here," said Simpson in a recent interview. "I hope to go to Washington taking the skills and experiences of what we've done here in Arkansas to make a positive impact on people with disabilities all across the nation."

The Arkansas Spinal Cord Commission offers our congratulations and wishes 'one of our own' well as he embarks on another adventure in his rehabilitation career.

In celebration of National Rehabilitation Week, September 19-25, 1993, Northeast Arkansas Rehabilitation Hospital in Jonesboro sponsored the first annual "Reach for a Star" awards banquet. Approximately 160 people attended the awards presentation Thursday evening, September 23. The two-hour program honored individuals and organizations in Northeast Arkansas who have made significant contributions to the lives of people with disabilities, or who have overcome disabilities themselves.

L.E. Sanders was the keynote speaker at the banquet where he addressed, "Living With a Disability." Mr. Sanders, injured in an automobile crash in 1945, had just recently returned from the annual National Spinal Cord Injury Association conference in Denver, Colorado where he had delivered the keynote address.

ASCC Commissioner Grover Evans served as Master of Ceremonies for the awards presentation. The Outstanding Parent Advocate award was presented to the parents of ASCC client James Taylor who sustained a diving injury in 1977. Outstanding Student awards were presented to ASCC clients Jeanette Hogan and Dana Matthews, both of whom were born with Spina Bifida. Personal Achievement awards, presented to individuals who had achieved life goals, went to Tom Withers, Elizabeth Liberto and Larry Sipes. Mr. Withers, who was injured in a motor vehicle crash, has become a skilled gunsmith. Ms. Liberto, born with Spina Bifida, has demonstrated marked improvement in physical and scholastic aptitude. Larry Sipes, who sustained his spinal cord injury as the result of a bicycle accident, has finished high school and is currently enrolled in vo-tech.

ASCC congratulates these clients on their outstanding efforts.

Survey, from page 1

of community ambulator, 6% were classified as household ambulators, 5% exercise/emergency ambulators and 40% were nonambulators. The remaining 4% were unknown or infants with no ambulation capabilities determined.

Wheelchair use: 50% of Arkansans with spina bifida use a manual wheelchair propelled by their self, 9% use a manual wheelchair propelled by someone else, 2% use a power propelled wheelchair and 34% do not use a wheelchair.

Braces: 44% use some type of leg braces.

Shunt: 73% have some type of a shunt in place. For those with a shunt, 80% were installed within the first month after birth. The most common shunt type is a ventriculo-peritoneal shunt installed on one side. 69% have had their shunt revised with most (77%) experiencing an improvement as a result. 24% have had an infection in their shunt at some time.

Pressure sores: 63% have had a pressure sore at some time in their life and 18% had a pressure at the time of interview. Of those who had had a sore at some time, 36%

had been hospitalized specifically for treatment of the sore.

Bowel Control: 23% have voluntary control of their bowel, 22% have no control, 33% have a scheduled bowel program that involves the use of aids, and 10% have a scheduled bowel program that does not use aids. The remaining 12% are infants or use another type of bowel program.

Bowel Assistance: 44% of the group indicated that they needed assistance with their bowel program.

Bladder Control: 44% use intermittent catheterization for voiding, 12% have voluntary control. 7% have scheduled voluntary voiding, and 27% use a diaper or other collection device full or part time. The remaining 10% are infants with bladder control not determined.

Bladder Assistance: 33% of the group indicated that they needed assistance with their bladder program.

Based on these preliminary findings, Arkansans with spina bifida appear to be a cross section of the general state population. Most are young and single and live with

their parents even after their education is complete. Pressure sores appear to be a problem for this group.

Additional findings of the Spinal Cord Commission's survey of Arkansans with spina bifida will be presented by Executive Director Cheryl Vines and Director of Research and Statistics Tom Farley at the annual conference of the Spina Bifida Association of Arkansas. The conference will be held on Saturday, October 23, 1993, at the Brandon Conference Center at Arkansas Children's Hospital.

GROVER EVANS NAMED SWIMMER OF THE YEAR

ASCC Commissioner Grover Evans attended the 32nd National Wheelchair Games July 19-24 in Boston, MA where he was named "Swimmer of the Year," as he went on to win six gold medals and setting two national records.

In June, Grover competed at the 15th Annual Southwest Wheelchair Regional Games and won six gold medals and set five new national records in swimming. He currently holds 10 national records in swimming (yard and meter).

Printed on recycled paper.

SPINAL COURIER

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